

# Our Broken Health Care System Is Failing People With Cancer

## Who Has Cancer in America?

The mother of your child's best friend. The man who waited on you at the hardware store last week. Your brother-in-law. The woman in front of you in the check-out line at the market. Your favorite teacher in high school. The homeless woman who's always at your subway stop. Your doctor. The eight year old son of the family three doors down. Your co-worker at the plant who brings doughnuts for everybody. Your minister. The teller at the bank. Your college roommate's wife. The farmer who grew the potato you'll have for dinner tonight. Your grandmother at the nursing home. The father of your paperboy. Perhaps, even you.

Right now, 8.9 million people in America are living with cancer. They will be joined by more than 1.2 million others who will be newly diagnosed this year—about 34,000 each day.<sup>3</sup> Overall, cancer is an equal opportunity disease—it strikes people of all ages, races, ethnicities, religions, cultures, geographic locations, and education and income levels. It strikes both the influential and the invisible among us. It kills more than a half million of us every year. And every person is at risk for cancer in his or her lifetime.

At the same time, certain cancers are known to be more or less common among specific populations, for reasons that may include varying combinations of lifestyle behaviors, genetic predisposition, and environmental exposures. For example, lung, bladder, esophagus, and oral cancers are most common

among current and former tobacco users. Skin cancers are more common among fair skinned people who have had excessive sun exposure. The chance of developing most adult tumors rises with increasing age, seemingly due to accumulating genetic errors, the aggregate effect of environmental exposures, and other factors.<sup>4</sup> Neuroblastoma and Wilm's tumor are among the cancers that occur almost exclusively in children and are believed to be due to inherited or very early gene mutations.<sup>5</sup> It is less clear why the prostate cancer rate among African American men is 60 percent higher than that of white men, why Vietnamese women have exceedingly high cervical cancer rates, or why nasopharynx and stomach cancer rates are unusually high among some Asian populations. Nor do we know why some Latino, American Indian, and other populations have lower than average rates for certain cancers.

Modest decreases in cancer incidence and mortality have been achieved in recent years,<sup>6</sup> yet cancer remains the second leading cause of death in the nation,<sup>7</sup> and is responsible for immeasurable fear, suffering, and hardship among both patients and their families.

## The Disconnect Between Cancer Research and Cancer Care Delivery

For some of the more than 100 distinct types of cancer, research has brought improvements in detection, diagnosis, treatment, and supportive care, providing improvements in survival and

quality of life. But many of the interventions that research evidence has shown to be effective are not reaching people throughout the country. The Panel illustrated this “disconnect” between the cancer research and cancer care delivery efforts (see Appendix B) in its 1999 report on the evolution and status of the National Cancer Program, and emphasized that this disconnect is not a failure of the research effort. Without question, the cancer research effort has been productive, and continued research is needed, both to expand basic research and to translate basic science discoveries into useful interventions; to improve cancer preventive, palliative, and end-of-life care; and to enhance our understanding and measurement of cancer care quality, including cancer communications effectiveness, treatment outcomes, and quality of life. But the current disconnect reflects the nation’s ongoing failure to organize, finance, and operate a health care system that assures access to appropriate cancer care and brings proven interventions to all of the population. In short, our health care system is broken, and it is failing people with cancer and those at risk for cancer—all of us.

## The Health Care System and Cancer—Who Is Underserved?

The National Cancer Institute’s (NCI) Special Populations Working Group has defined the term “underserved” as referring to “populations at risk of poor physical, psychological, and/or social health who experience a lack of sufficient community, clinical, or individual resources to effectively meet their needs.”<sup>8</sup> This definition encompasses groups that are not benefitting from available options for improving health and reducing disparities in the United States. In this sense, underservice is a dynamic state into which an individual may move in or out, and varies by type of disease and disease stage. The term “medically underserved,” refers more narrowly to Federally designated geographic areas with poor access to health care providers and medical services.

Thus, while the underserved most often are thought to be the poor, minorities, the uninsured, and those in medically underserved areas—populations that indeed are represented disproportionately among the underserved—a person also may be underserved for cancer care even though he or she has insurance, if that coverage does not provide needed services at a time of health care crisis, or to prevent and detect disease. Moreover, even those with comprehensive insurance may be underserved if their health care provider lacks information about the most appropriate evidence-based cancer care, including clinical trials.

## Health Care System Changes

Although the fee-for-service (FFS) system that dominated health care financing prior to the advent of managed care was a major contributor to spiraling health care costs, changes in the structure and financing of the health care system in recent years have had profound effects on the quantity and scope of cancer care provided, provider payments for care, and the system’s capacity to care for the indigent. Much of the change has been due to cost containment pressures from managed care plans and “managed” FFS plans that are the payers for a growing percentage of the population in both private and publicly funded insurance settings. “Gatekeepers” in many health plans restrict referrals to specialists, exclude the use of drugs not on a health plan’s formulary, limit supportive and rehabilitative care, deny access to clinical research trials, refuse to pay for the routine care costs of those who participate in trials, and set strict limits on payments for medical equipment and prostheses.

In addition, reimbursements to providers of all types have fallen steadily. To compensate, physicians in office and institutional settings are under pressure to see more patients in less time. Physicians in office settings may suffer financially or be dropped from a health plan’s provider roster (thereby losing patients) if,

in the judgment of the plan, they spend too much time with individual patients, make too many referrals, or order too many tests.<sup>9</sup>

State-of-the-art cancer care is increasingly expensive and technology driven, but with reduced profits and reimbursements, physicians and institutions, particularly those other than major metropolitan medical centers, are finding it increasingly difficult to buy the equipment and supplies needed to provide the most effective tests and therapies. This legitimate need to upgrade cancer care technology for the benefit of patients is to be distinguished from unnecessary duplication of resources often driven by competition between providers, particularly in urban areas. Reimbursement reductions also are affecting hospital staffing patterns (particularly for non-physician personnel), the willingness and ability of institutions or individual physicians to provide care for those unable to pay, and the ability of cancer patients to receive second opinions and appropriate care alternatives.

For many patients, these health system changes have resulted in a fragmented, often bewildering system in which cancer and other health care must be obtained only at facilities and from providers under contract to the health plan. In this setting, continuity of care may be compromised, patients may no longer have regular and trusted providers, supportive services are minimal or non-existent, and responsibilities for patient education and appropriate sharing of medical information frequently fall to patients themselves. For some, there simply is no care available.

## Distribution of Cancer Care Resources

People living in rural, frontier, geographically isolated, and impoverished inner city areas suffer the most from the uneven distribution of cancer care resources and providers—a key element of underservice in these populations. This uneven distribution of resources and personnel is longstanding, and may be worsening

as reimbursement changes make it less and less attractive for providers to establish and maintain practices in rural and inner city areas. Provider reimbursements for most aspects of care are lower in rural areas compared to metropolitan settings. Facility and certain other overhead costs are lower in rural areas, but the reimbursement differences appear to exceed substantially these differential costs of providing care. With sparse populations in rural and frontier areas, providers cannot sustain operating revenues or accumulate capital to buy new equipment and supplies by seeing more patients.

## The Underinsured

In the current health care environment, simply having insurance is no assurance of appropriate care, particularly for complex diseases such as cancer for which treatment is expensive and often lengthy. At least 31 million insured Americans are estimated to be inadequately insured for a catastrophic disease such as cancer.<sup>10</sup>

This estimate of the underinsured does not include Medicare beneficiaries, a large percentage of whom live on fixed incomes. Many cannot afford Medicare Part B premiums (for outpatient and all physician care) or Medicare supplemental insurance policies, and so are at risk for all health care expenses incurred outside of a hospital setting. At this time, outpatient prescription medications are not covered under Medicare; these can total several hundred dollars per month even for patients who do not have cancer. Many elderly Americans routinely must choose between buying food or their medications. Some report reducing their dosages, only buying part of a prescribed amount of medication, or sharing prescriptions with family members or friends.

Lower-income employed people who can afford to participate in employer-sponsored group insurance plans often choose limited coverage with high deductibles and copayments in order

to lower premiums to affordable levels, but then find their coverage inadequate (both in terms of non-covered costs and access to the most appropriate care) when diagnosed with a serious disease such as cancer. These families find they must deplete their savings and sell their homes and other assets to pay the non-covered costs of cancer. Middle-income people can likewise be devastated financially by the costs of cancer care, though they initially may have more resources, including family support, on which to draw. Additionally, many people with cancer lose their health coverage when either the patient or spouse loses the job through which insurance was offered. Many cannot afford to continue coverage under provisions of the Consolidated Omnibus Budget Reconciliation Act (COBRA)<sup>11</sup> that enable such workers to maintain their health insurance under an employer's group plan if they pay the full monthly premium.

People with Medicaid or other publicly funded medical assistance typically must accept whatever care is offered since they have no income with which to purchase private insurance or pay out-of-pocket for additional care. Some populations are more likely to rely on public insurance; more than one-fifth of Hispanics and over one-fourth of African Americans have public insurance only (including Medicare), compared to one-tenth of whites.<sup>12</sup> In addition, many cancer care providers hesitate to accept Medicaid patients because of low reimbursement rates and slow payment processing.

## The Uninsured

Currently, 44 million people in America have no health insurance at all,<sup>13</sup> and therefore little access to health care services, including cancer screening and cancer care. When they receive care at all, this population tends to rely on special screening programs, charity care, and care provided by hospital emergency departments. According to a 1999 report of the National Coalition on Health Care, under

favorable economic conditions the number of uninsured non-elderly (those under age 65) is projected to rise to 52 to 54 million by 2009; if a recession occurs, that number will likely jump to 61 million.<sup>14</sup> An analysis of the 1999 Current Population Survey (CPS) indicated that in 1998, ten states had uninsured rates in excess of 20 percent of their non-elderly population, and the uninsured rate among the non-elderly nationwide was 18.3 percent.<sup>15</sup> Uninsured rates also appear to be affected by the availability and eligibility requirements of state-level Medicaid or other medical assistance programs. Data from the National Center for Health Statistics (NCHS) indicate that an important factor in uninsurance trends is the decline in private insurance coverage, particularly for people aged 18 to 44 years, whose rate of coverage fell from 77 percent in 1984 to 69 percent in 1997.<sup>16</sup> A recent study indicated that near-elderly (aged 55 to 64) working women with health problems are more likely than younger workers to lack employment-based health insurance, to be uninsured, and to lack sufficient income to purchase insurance.<sup>17</sup> Changing employment trends appear to be exacerbating the problem of uninsurance. Many larger employers are cutting the size of their full-time work force and replacing these employees with part-time or contract workers who typically do not receive health benefits.<sup>18</sup> More people are now working at small companies that cannot afford to offer health coverage. Fewer employers of all sizes are offering health insurance. A growing number of the uninsured appear to be former welfare recipients who have moved into the workforce. Though no longer eligible for Medicaid, they do not have health coverage through their new jobs.<sup>19</sup> Nationwide, 84 percent of the non-elderly uninsured are working adults and their children.<sup>20</sup>

The CPS data analysis also indicates that while 53 percent of the uninsured are non-Latino whites, ethnic minorities have disproportionately high uninsurance rates—38 percent of Latinos, 24 percent of African Americans, and

22 percent of Asian American/Pacific Islanders are uninsured, compared with 14 percent of non-Latino whites.<sup>21</sup>

## Evidence of Unequal Treatment

When a person has a diagnosed or suspected cancer—any person, with any cancer—he or she needs immediate help. That means complete and understandable information, and the most appropriate care. But some people with cancer, even the same type of cancer at the same stage of disease, fare better than others for reasons that have little or nothing to do with the biological aspects of their disease. Growing evidence indicates that much of the disparity in cancer outcome has to do with the type, timeliness, and continuity of cancer care that people do or do not receive.

The impact of poor quality and unequal treatment on specific patient groups is being documented with increasing frequency and clarity. For example, a recent review of more than 50 studies of colorectal cancer treatment and outcome found that older, minority, and poorer patients tend to receive substandard care and have less favorable outcomes than those who are younger, white, or more affluent.<sup>22</sup> Other studies have found that African Americans are less likely to receive potentially curative surgery for early stage lung cancer<sup>23</sup> and less than the minimum expected care for breast cancer<sup>24</sup> compared with white patients having equivalent income, access, and stage of disease. Both men and women of higher income are more likely than those with lower incomes to obtain cancer screening<sup>25,26</sup> that can result in earlier detection of disease and in many cases, improved survival. Similar disparities among population groups have been documented with regard to non-cancer illness, including prescriptions for and access to pain medication,<sup>27,28</sup> use of cardiac catheterization following a heart attack,<sup>29</sup> and managed care plan approvals for emergency room care.<sup>30</sup>

Efforts to address disparity and quality issues also are accelerating as awareness and documentation of these problems increases. The Department of Health and Human Services (DHHS) is pursuing an initiative to eliminate health disparities by 2010, and individual DHHS agencies have been charged to implement efforts in support of this goal. For example, the DHHS Office of Minority Health has published final recommendations for culturally and linguistically appropriate service (CLAS) standards for health care.<sup>31</sup>

Specific to cancer, NCI has established a Center to Reduce Cancer Health Disparities<sup>32</sup> and also has established research programs to address quality of cancer care issues and to advance outcomes research. The President's Cancer Panel,<sup>33</sup> the National Cancer Policy Board,<sup>34, 35</sup> the Institute of Medicine,<sup>36, 37, 38</sup> the National Cancer Advisory Board,<sup>39</sup> and others<sup>40, 41, 42, 43</sup> likewise have studied and continue to explore issues of cancer and other health care quality, equity, and outcome. All of these efforts, together with the accumulating body of qualitative evidence, a part of which is contained in the next section of this document,<sup>44</sup> can be used to educate and guide policymakers to create a health care system that better and more equitably serves the public.